



Empowering Partnerships
Preparing People with Dementia
to Partner with Researchers

LiveWell
DEMENTIA SPECIALISTS

FOR IMMEDIATE RELEASE

LiveWell Project Funded to Engage People Living with Dementia as Research Partners

Plantsville, CT, June 12, 2019 – LiveWell Dementia Specialists, a leading national voice in dementia care, received a \$250K award for a ground-breaking project to more effectively engage individuals living with dementia as “partners” in the dementia research process. The “Empowering Partnerships” project is the first of its kind in the United States, designed to develop methods and approaches to enhance future research in dementia care by strengthening and expanding collaborations between researchers and persons living with dementia. The project was inspired by a key recommendation made at the 2017 National Research Summit on Dementia Care to “Fund more research on how people living with dementia and their caregivers can be partners with researchers.”

“This project was founded in a pivotal moment of voices uniting to respond and deliver ground-breaking research methods. Persons living with dementia and researchers will discover and co-create, ‘how’ research can be done differently, and most importantly ‘why’ it needs to be done in the first place.”... said Heidi Gil, President & CEO, HoodenPyleGil, Project Lead.

LiveWell will lead a team of local and national stakeholders to create a network of persons living with dementia, family care partners, and researchers to partner in all aspects of person-centered outcomes and clinical effectiveness research. LiveWell will be joined by program partners from Yale University School of Medicine, University of Connecticut Center on Aging, the National Alzheimer’s & Dementia Patient & Caregiver-powered Research Network (PPRM) and the Alliance for Aging Research. Leading the project with LiveWell is HoodenPyleGil (HPG), a systems research and innovation lab based in Milford, CT.

“This project is critical for dementia research. People with every other chronic disease and disability are being brought to the research table and yet people with dementia aren’t even considered. They are immediately marginalized even though can actively participate in research for years if we access their retained strengths and learn to compensate for their cognitive disabilities”, said Stephani Shivers, LiveWell Chief Operating Officer, Community Services, and Project Co-Lead.

The \$250K funding award, comes through the Eugene Washington PCORI Engagement Awards program, an initiative of the Patient-Centered Outcomes Research Institute (PCORI), based in Washington, D.C. PCORI is an independent, non-profit organization authorized by Congress in 2010 to fund comparative effectiveness research that will provide patients, their caregivers, and clinicians with the evidence needed to make better-informed health and healthcare decisions. PCORI is committed to seeking input from a broad range of stakeholders to guide its work.

According to Jean Slutsky, PCORI’s Chief Engagement and Dissemination Officer, *“This project was selected for Engagement Award funding because it will build a community equipped to participate as partners in Clinical Effectiveness Research and develop partnerships and infrastructure to disseminate PCORI-funded research results. We look forward to working with LiveWell throughout the course of their 2-year project.”*

The Empowering Partnerships project aims to build the capacity of people living with dementia to be involved in the research process and advance their engagement in research by:

- Expanding and strengthening the Dementia Peer Coalition – a peer to peer network of individuals living with dementia
- Developing and implementing a training program on research concepts and ways to co-partner on study design and methods including specialized education on how to leverage the strengths and retained abilities of people living with memory and cognitive changes from dementia
- Identifying, prioritizing, and disseminating research topics important to persons living with dementia
- Producing and disseminating a Toolkit for project replication

The Dementia Peer Coalition (DPC), led by and for those living with dementia, developed a peer-to-peer network focused on peer support, advocacy, research, education, and volunteerism. This project will catalyze the DPC’s efforts to prepare, expand and sustain a network of people living with dementia to engage as partners in aspects of dementia care research including project design. *“I need researchers to partner with me, evaluate what matters, and validate what is working”*, said Bob Savage, a person living with dementia and Dementia Peer Coalition (DPC) Co-founder. Geri Taylor, also living with dementia, adds *“Speak with me, not for me.”* That is precisely what this project aims to accomplish.

“As researchers, we think that because we read the scientific literature that we know what benefits are most important to people living with dementia. There may be other outcomes that we didn’t even consider that people living with dementia could tell us about. The same goes for care partners”, said Dr. Richard Fortinsky, Ph.D. Professor, UConn Center on Aging.

In addition, LiveWell and program partners will network nationally for opportunities to align the collaborative engagement approach in a prioritized research agenda, identifying specific research topics to be pursued. Through the project four to five research agenda items will be prioritized by people living with dementia, care partners, and researchers.

As the 2-year project progresses, key aspects will be captured in a program Toolkit, which will provide others in the field with a how-to guide to replicate the work conducted under the Award, thus extending the impact beyond participants involved in implementing this project. The toolkit is to include webinars, podcasts, along with peer-driven recruitment strategies, the training curriculum, strengths and capacity assessments and lessons learned from the program execution.

About LiveWell Dementia Specialists

LiveWell Dementia Specialists is a comprehensive dementia services provider and dynamic thought leader at the cutting edge of critical thinking, caregiving and policy development. LiveWell initiatives are recalibrating the way people living with dementia are viewed, respected and supported, by their families and communities. Formerly the Alzheimer’s Resource Center, founded in 1990, LiveWell provides comprehensive services for people living with dementia and their families including dementia care navigation, specialist services, a day program, assisted living and skilled nursing communities. LiveWell also leads the Dementia Friends movement in Connecticut. 'Dementia Friends' are people who learn about dementia and turn their understanding into local action that helps build dementia-friendly communities.

For more information about LiveWell visit www.livewell.org, the Empowering Partnerships project visit empoweringpartnerships.livewell.org and for the Dementia Peer Coalition visit www.dpc-ct.org. For more information about PCORI’s funding to support engagement efforts, visit <http://www.pcori.org/content/eugene-washington-pcori-engagement-awards/>.

Media contact: Brian Connolly, LiveWell, 860.628.3037, bconnolly@livewell.org